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Beyond Bingo: Enhancing Quality of Life in the Face of Death for Hospice Patients with Dementia Through Integrated Expressive Arts Therapies, Development of a Method

Jeanie Cooper Carson

Lesley University, jcarson2@lesley.edu

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Beyond Bingo: Enhancing Quality of Life in the Face of Death for Hospice Patients with
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Capstone Thesis

Lesley University

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Jeanie Cooper Carson

Expressive Arts Therapies

Denise Malis, Thesis Instructor

Abstract

This paper explores ways integrated expressive arts therapies (EAT) used with individuals with dementia in hospice can help facilitate living well in the face of dying. While research is limited regarding use of EAT with this population specifically, much significant research has been conducted to support the effectiveness of the employment of various creative arts modalities with individuals with dementia and also on hospice. Building on this research, the author developed and implemented an integrated EAT method with members of this population living in long-term care facilities in Greater Boston in the context of the pandemic of 2020-21. This paper will discuss the literature that informed the method, what took place during the implementation of the method with two patients, and what was learned from observing and experiencing play with those experiencing a myriad of losses. Description of hospice visits centered in co-creating in dynamic therapeutic relationships, illuminates particular ways EAT helped two individuals experiencing cognitive decline and facing death access non-verbal and spontaneous creativity and the wisdom of the body in the here and now. It conveys how EAT was used to engage senses and facilitate a sense of connection through exploration and expression of a range of emotions. The paper argues that EAT's connection to play through the use of the imagination makes it particularly well suited to this population with rich potential for enhancing quality of life when facing death. Finally, the paper suggests avenues for future research and application of this method beyond the pandemic.

Keywords: Expressive Art Therapy/Therapies, hospice, palliative care, good death, dementia, person-centered care, pandemic

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Introduction

The truth is, once you learn how to die, you learn how to live.

Mitch Alborn, *Tuesdays with Morrie*

We all will die, although we often live in seeming denial of this fact. In the face of the global pandemic today, the truth that each of us lives in the shadow of our mortality has hit home with stunning force. This is all the more impactful for older adults, given eight in ten of those who have died as a result of the COVID-19 pandemic were over 65 years old (Center for Disease Control and Prevention, 2021). In turn, the question— What does it mean to have a good death? — has become increasingly pressing for older adults and their loved ones.

There is little consensus about answers to this big question, but researchers and palliative care and hospice providers do agree that dying well involves living well in the last chapter of life, and key components of this include comfort (social, emotional, and spiritual as well as physical) and dignity, even as they define these terms differently. The question this thesis explores is: How can the use of expressive arts therapies on behalf of individuals with dementia in hospice promote aspects of living well in the face of dying? This thesis argues that grounding notions of quality of life in a relational conception of personhood is key. It provides an overview of research showing the efficacy of interventions using various arts modalities for individuals with dementia to enhance quality of life and then builds on these findings by providing an intermodal expressive arts therapy method. A method that breaks with limiting cultural norms for determining what lives are worthy of respect and worth living, ones that privilege cognition and

memory as the mark of social value. A method grounded in accessing playful imagination and the wisdom of the body in the here and now through co-creating in therapeutic relationship. The thesis tracks the impact of the method as used with two terminally ill individuals with dementia living in long-term care facilities in the Boston area and draws conclusions for possible future modifications.

What is Hospice and What Are Its Goals?

Hospice care worldwide focuses on quality of life for people and their caregivers who are experiencing an advanced life-limiting illness. A person on hospice is attended to by an interdisciplinary team whose goal is to offer compassionate care so that that person may live as fully and comfortably as possible. This team most often includes nurses, aides, a chaplain, a social worker, and/or a counselor (American Cancer Society, 2021). Hospice's sister discipline is palliative care and distinguishing between the two is important. A person qualifies for hospice when their prognosis is six months to live or less. A person on hospice can no longer receive curative treatments. Palliative care, by contrast, can be given at the same time as curative treatments at any stage. In the US, the billing is another difference; all hospice services are covered under Medicaid and Medicare while palliative care is paid for by insurance or self. The goals are the same, however: offer comfort care, reduce stress, provide complex symptom relief from serious, life-limiting illness, and reduce physical, emotional, spiritual, and psychosocial suffering (National Institute on Aging, 2017). As founder of the hospice movement Dame Cicely Saunders explained, this boils down to giving patients a sense of mattering: "You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die" (American Cancer Society, 2019).

Research on Living Well in the Face of Death

Next, before addressing particular concerns of persons on hospice with dementia, a large subgroup of older adults with terminal illness, it is important to consider research and conclusions about what constitutes quality of life in the face of death for the majority of older adults. The context of this research is conceptions of positive or successful aging, a major focus of gerontology research from the late 1990s to the present. The seminal study of Rowe and Kahn's (1997) defines positive aging as having 1) low risk for disease, 2) ability to maintain high mental and physical functioning 3) active engagement in life. Other studies in the US underscore functional independence as the mark of successful aging (Lowry et al., 2012). This positive aging research had not taken into consideration experiences and values of terminally ill individuals.

The spiritual strength that enabled older adults to face difficult events, particularly dying, with courage is a quality noticeably absent in definitions of positive aging. In turn, research on living well in the face of death aimed to fill this gap. A mixed methods research study of older adults in four hospices in Kansas and Illinois by Nelson-Becker (2013), for example, showed that resilience is salient in participants' narratives about dying well, the quality that led to a sense of spiritual strength and well-being. A key sub-theme that emerged in Nelson-Becker's (2013) research was a sense of engagement in life that involved reciprocity and social concerns. Another subtheme was having the chance to reflect on and share views on what is important in life. Beyond identifying common themes, this research ultimately served to broaden the definition of living well in the face of death to fit the dynamic, individualistic narratives gathered and analyzed: "Dying well is ultimately about living fully and consciously in whatever way one chooses until the moment of death" (p.88), Nelson-Becker concluded. This aligns with what hospice and palliative care physician B.J. Miller (2015) has observed. Beyond common themes

of wanting to find a sense of closure and peace, to be “unburdened and unburdening,” he encourages us to keep in mind that “dying people are living and to treat them accordingly. There is so much room for personal preference” (12:40). For these American practitioners and researchers, personal choice in deciding what dying well looks like is paramount.

Cultural Variations

Hospice and palliative medicine is a recognized medical subspecialty in the United States and internationally. Developed countries utilize the vast majority of hospice and palliative care resources (The Worldwide Hospice Palliative Care Alliance, 2021). Roughly 85% of the people dying around the world do not have access to safe forms of pain relief. Exploration of the variations in hospice and palliative care internationally is beyond the scope of this paper. That said, it is important to note that even within more developed countries, cultural variations must come into consideration when providing quality hospice care. Much can be learned from cross-cultural reviews of literature on positive or successful dying that stress ways that differences in cultural background impact the concept of good death.

Consider, for example, a qualitative study of 180 Buddhist adult patients with cancer plus their families in Thailand by Chundaprasirt et al. (2019). These researchers found that all participants held three main concerns: positive state of being experience in facing end of life, concern with quality of life, meaning feeling satisfaction with one’s life and care, and compassionate care as defined by Buddhism. Researchers’ coding showed some divergence in subthemes between stakeholder groups. For families, a good death not only meant valuing patient wishes and valuing patients as dearly loved, it meant helping patients understand death as a natural process, allowing Buddhist rites to be performed, and managing finances. Furthermore, honoring the belief that family members need to “pay back their debt of life” to loved ones

emerged as a component of dying well. However, the Buddhist family member participants underestimated their loved ones and patients' concerns with not being a burden, psychological as well as physical comfort, and psychological and spiritual preparation for death (Chundaprasirt et al., 2019).

Unlike their Thai counterparts, American researchers who conducted a literature search and analysis raised the widely voiced concern that there is no such thing as an external criterion of a good death and that it is more dependent on the unique perspectives of the dying individual. We see this in two of the most comprehensive, scoping reviews of the literature (Meier et al., 2016; Kirkoria, 2020) that examined published, English-language, peer-reviewed reports of qualitative and quantitative studies that provided definitions of a good death. Unlike the review of literature in predominantly Buddhist communities by Chundaprasirt et al. (2019), no cultural consensus was revealed in extensive literature reviews by Meier et. al. (2016) and Kirkoria (2020). These findings point to the need for a stance of cultural humility and collaboration with culturally competent community members when serving hospice patients in any setting.

Research on Living Well with Dementia, a Leading Cause of Death

A subcategory of research on living well in the face of dying focuses on participants with cognitive decline, those who have lost much of their capacity for language and access to memory, including those with advanced dementia who cannot reflect on and verbally communicate a sense of their life history, purpose, or legacies, or function independently. This group is a very important one to consider. Worldwide, around 50 million people have dementia, and there are nearly 10 million new cases every year. That figure is expected to treble to 135 million by 2050 (Goldstein-Levitas, 2016). Dementia is one of the leading causes of death in the

US. Researchers estimate that if all forms of dementia were added together, it would be the third leading cause of mortality in the US (Berman, 2020).

First, before considering research on living well with dementia, what is meant by the term dementia? What are its effects? Dementia actually refers to a cluster of medical conditions that involve abnormal changes in the brain and not just one disease (Ho, et al., 2015). There are 13 different distinct types of dementia, with 60 to 80 % being Alzheimer's disease (AD). The second most common form of dementia is vascular dementia (VD). VD results from injuries to vessels that supply blood to the brain, often after a stroke or series of strokes, and accounts for 5-10% of cases of dementia (Newman-Bluestein & Chang, 2017). Damage to brain cells is the root cause of dementia. Because clear communication between cells is interrupted, thought process, emotions, and behavior become negatively affected to varying degrees (Alzheimer's Association, 2019). For example, in AD the hippocampus, the region of memory and learning processes is the first to be damaged. In turn, memory loss is often the earliest sign of AD. In the areas of the brain involved in spatial navigation, language, memory, thinking skills, and recognition an increasing cognitive degeneration develops (Ho et al., 2015).

Along with issues with short-term memory, those with dementia become unable to do routine tasks of daily life, such as paying bills, making meals, and keeping track of personal belongings like keys or wallets. (Alzheimer's Association, 2019). As the disease progresses, challenges in engaging in activities, adapting to the environment, and processing sensory stimuli most often increase. Self-soothing and maladaptive behaviors, including repetitive movements, primitive vocalizations, aggression, and wandering that individuals with dementia exhibit are all responses to effects of sensory deprivation (Goldstein-Levitas, 2016).

Such behaviors have fueled a conception of dementia as an undignified existence, life not worth living, and have had a tenacious hold in popular culture, notes Dekker (2018). Notions of persons living with dementia as empty shells, passive victims, and sufferers, those who have experienced a loss of self, have engendered widespread fear of dementia and the belief that only a very low quality of life is possible for those who have it (Marthardt & Spira, 2013). This flows from the medicalization of death and a cultural discourse that establishes limiting norms of personhood and health, argues Macdonald (2018). She writes, such notions “privilege cognition and memory as the mark of social value and stunt the ways we are taught to think of selves in relationship from birth to death” (p. 396). Because an individual must rely on others for help with basic functions of daily living, the diagnosis of dementia, an incurable and fatal disease evokes another layer of upset beyond that of other terminal diagnoses, McDonald (2018) observes; this is because it is not the disease itself that sparks fear but what it points to in terms of the fundamental understanding of what it means to be a person. McDonald (2018) writes, “Dementia confronts because it seems to bring death into life, implicitly questioning what life, relationship, and death are about” (p. 396). It is the very notion of rugged individualism and independence that dementia throws into question.

To counter negative conceptions and doubts that persons with dementia can experience quality of life even in the face of death, there has been a movement away from myopic focus on biomedical problems to an approach known as Person Centered Care (PCC). This involves seeing past manifestations of disease to focus on the individual psycho-social determinants of health. It has been an important research and trend of the past two decades to improve care for those with dementia. According to the PCC model, a person’s unique biography and preferences always need to be taken into consideration (Villar et al., 2019). Beyond this, in the context of

caring for those with dementia, a more relational view of selfhood has taken hold in the PCC model, spurred by efforts to counter negative stereotypes that give rise to hopelessness (Marthardt & Spira, 2013). The revised view of PCC for dementia patients centers on quality relationships of care and not maintaining functional independence. In turn, these are the terms invoked in interventions aimed to help dementia patients live well in the face of death.

McDonald (2018) further explains why interventions that involve making an ontological shift to embrace the meaning of personhood as relational and heightening nonverbal awareness and communication. have helped transform lives of persons with dementia (and those who care for them) and improved quality of life. Loss of the ability to speak prompts the display of nonverbal expressions such as agitated body language and screaming, MacDonald (2018) stresses. She cautions against viewing nonverbal behaviors as signs of emotional or sensory collapse or loss of interest in communicating. She urges those working with dementia patients to become more attentive observers so as to more readily recognize movements that suggest distress or pain and expand their repertoire on nonverbal strategies such as use of “touch, visual stimulation such as direct eye contact and pictures, sounds that soothe (voice tone, music), and sight” (p. 392).

Arts Therapies with Individuals Living with Dementia

Arts therapies and counseling psychology, disciplines that emphasize creative connections and strengths, including resilience in the face of developmental challenges (Gelso, et al., 2014), are well-positioned to work toward better understanding and caring for all people at the end of life. Moreover, arts therapies’ benefits for people with dementia are well established. As Schneider (2018) demonstrated in her systematic review of use of arts in dementia care, the arts foster dignity, reciprocity, lack of stigma and social integration. Vaartio-Rajalin et al. (2020)

identified features that help explain why arts are so beneficial for adults with cognitive decline: they “facilitate self-expression, social interaction, communication, sensory stimulation, and emotional relief in a failure free environment” (p.102). Moreover, reminds Bastings (2006), all forms of creativity are not dependent on memory. Creative processes are used to evoke memories, enable people to communicate about their experience, reinforce identity and strengthen relationships.

Integrated Expressive Arts Therapy (EAT) and Dementia

Integrated expressive arts therapy (EAT) (also known as intermodal or multimodal arts therapy) approaches are based on our ability to access and stimulate the imagination by shifting from one art form or one art modality to another (Malchiodi, 2005) and are well-suited to working with people with dementia . The concept of intermodal transfer distinguishes EAT from neighboring disciplines such as art therapy, music therapy, dance therapy, or drama therapy which all use just one art form. EAT invites clients or patients to use one expressive modality as a source of reflection and exploration about another form, e.g., a poem written about a drawing, a painting about a movement or role play, and so on. To facilitate meaning making about experiences, feelings and/or perceptions, while sometimes writing is used, more often than not the therapist invites nonverbal expression, that which taps the senses. Through use of touch, imagery, and/or carefully guided body movements, memories and stories often emerge that would never come out in conversation. The focus of an EAT session is on letting go and encouraging a creative process that facilitates a client’s unique expression, experimentation, sensory stimulation, discovery of personal meaning, awareness, understanding, and sense of connectedness. EAT is grounded in the notion that the agent of healing that all expressive forms have in common is human imagination (McNiff, 1992). McNiff distinguished this from creativity

and stressed that making fully formed products of self-expression that achieve a novel aesthetic value is not the goal. The medicine is in the process.

EAT helps people learn to play again, to let go of what they know, and discover the importance of beginning fresh. Experiences that involve pretending and all forms of imaginative play open up opportunities for trying out inventive solutions, ones that can lead to surprising and lasting transformations. These may include reconciling emotional conflicts, fostering self-awareness, managing behavior, reducing anxiety, increasing self-esteem, developing social connections, and even symptom relief. People who may be otherwise restricted in their ability to use imagination in problem solving may find EAT particularly beneficial. For all these reasons, EAT is a very effective approach in working with individuals living with dementia.

There has not been much research specifically on intermodal or integrated EAT to demonstrate its effectiveness for individuals living with dementia, as keyword searches indicate. However, there is much research on modality-specific interventions to draw upon, interventions that involve fostering relationships of care and employing sensory engagement to focus on the here and now to improve quality of life in the face of death. An awareness that people with dementia maintain – or in some cases even increase the ability to respond emotionally to their environment – has been growing during the past decade (Newman-Bluestein & Hill, 2010).

Take, for example, effectiveness of dance movement therapy (DMT) for groups of individuals living with dementia. Nyström and Lauritzen (2005) found that DMT groups facilitated rich and varied nonverbal expression in terms of both form and content (p. 297). Without speaking a word, participants conveyed thoughts and feelings and creative ideas in a space that created interplay between fantasy and reality where emotions and thoughts could be expressed symbolically through movement.

Mallory Barnes (2018) developed and implemented a method employing Chacian ideas in DMT groups; significant gestures were mirrored at the right time (and/or words and tone of voice) and for only as long as a person seemed to accept this. This fostered trust and a felt sense of safety that led to risk taking in relationships. Barnes's (2018) approach was grounded in notions of personhood counter to Western culture's privileging of reason over relationships, caring, and community. Group members experienced a positive sense of spiritual well-being freed from what Swinton (2012) has called the malignant "hypercognitivity" (p.176) of the current age. They also opened a pathway for caregivers to learn about how identity can be experienced in the here and now, identity not fixed in norms of prioritizing cognition and memory and created networks of care and connection in which individuals with dementia experienced a sense of being valued in their communities.

Kinney and Rentz (2005) study of 12 participants in a program that incorporated visual arts as a vehicle for nonverbal self-expression, *Memories in the Making*, also demonstrated ways arts enhance quality of life for individuals living with dementia. They concluded that during the program "significantly more interest, sustained attention, pleasure, self-esteem, and normalcy" (p. 220) was evident compared to other structured activities. Of note is the fact that this study only included participants in the early to middle stages of dementia and not those with severe dementia.

Cover (2012) conducted qualitative research on use of bibliotherapy with dementia patients institutionalized in a geriatric private clinic, the Policlinico Italia of Rome. This investigation also demonstrated the efficacy of interventions employing expressive art therapies to build creative connections that enhance the lives of those with dementia facing death. Cover (2012) noted:

Interacting with people affected by senile dementia means coming into contact with multiple frontiers. Borders of existence, for senior citizens are near death; borders of cognition, because dementia imposes distortions. However, it also produces creative possibilities, as it privileges the tactile, auditory and emotive canals with less emphasis on rationality” (p. 3).

Cover’s work supplements abundant empirical evidence for the multifold benefits of storytelling and reminiscing to help individuals improve quality of life, cope, facilitate personal growth, continue or adjust sense of identity, and more (Hesse, 2019). This study demonstrated that not just telling stories, but hearing stories contributes to enhanced quality of life, living well in the face of death.

The impact of drama therapy on the quality of life of individuals with dementia was studied by Kaaniste et al. (2015). Developmental Transformations (DvT) techniques were used in drama therapy groups. The foundation of this technique is free play. The goal of these groups was to offer a nonjudgmental, nondirective open space for expression through movement, that would foster both independence and personal identity in dementia patients. “A sense of connection with others, confidence to express feelings, spontaneous interaction, engagement of imagination, shared memories and motivation” was among core themes they identified in participants (Kaaniste et al., 2015, p.41).

Moreno-Morales et al. (2020) conducted a systematic review and meta-analysis to address the question: do interventions using music therapy (MT) with people living with dementia impact cognitive function, quality of life, and/or depressive states? Their results showed that cognitive function, as well as quality of life after the intervention and long-term depression improved with MT. However, they found no evidence for improvement of quality of

life in long-term and short-term depression in people living with dementia. One limitation is that not all the studies involved a registered music therapist (RMT) and instead were delivered by nurses or psychologists. Despite this, Moreno-Morales et al. (2020) concluded music could definitely be a powerful treatment strategy. And they called for future clinical trials aimed to design standardized protocols depending on the nature or stage of dementia so that they can be applied together with current cognitive behavioral (CBT) and pharmacological therapies.

Research by Graham-Pole and Lander (2008) lends further support to the claim arts therapies help dementia patients live well in the face of death. Graham-Pole and Lander focused on the question, what capacity does art have to offer insight and resolution in professional/family care partnerships and health in the end of life? The experiential and narrative data and analysis by Graham-Pole and Lander (2008) provided evidence for the power of metaphor in story and relationship through art making, including that made on behalf of patients. Even though the subject was loss, more images of health/wholeness than disease/disability were evoked in the themes identified in their analyses. Through prolonged engagement and persistent observation, they concluded that in both informal and formal settings, loving, authentic, artful relationships in the face of loss clearly have healing power. What emerges from these stories is what they call an “evanescent–preservable continuum”. By preservable Graham-Pole and Lander mean writings, paintings, drawings, sculpture and so on. On the evanescent side of the continuum are those “fleeting works of art, like the touch of a hand, a silent embrace in time of need, a chance interchange of close attention and loving intention; each capable of healing body, mind and spirit of both giver and receiver” (p. 3).

Investigations by Swinnen and de Medeiros (2017) underscore the power of play to enhance quality of life for individuals living with dementia. These researchers focused on two

participatory art projects using poetry and storytelling, TimeSlips (TS) and the Alzheimer's Poetry Project (APP). They used the methodology of humanistic inquiry (HI). HI brings imaginative skills to the reading of creative writing in a systematic interpretative process. The researchers served as participant observers for 10 weeks in the participatory arts programs (TS and the APP) at two residential facilities for people with moderate and advanced dementia in the Netherlands, De Beyart ($N=14$) and Scharwyerveld ($N=11$). They then analyzed field notes, audio recordings, flipcharts, notebook pages of responses, and transcriptions of stories and poems. As humanists/poets doing close readings and textual interpretations, they used their fine-tuned imaginations to ascertain what constituted evidence of "play," where meaning was derived from play, how and when poetry exchanges became an increasingly imaginative play, when original thoughts and gestures in improvisation and interactive play began to emerge, and so on. They made no conclusions about the effectiveness of play interventions. Rather, through prolonged engagement, persistent observation, and in depth, creative HI analysis, they illuminated the individuals behind the condition in these particular residential care centers in the Netherlands, and effectively demonstrated the quality of joy and connection in the "here and now" that participation in TS and APP brings them.

The research of Swinnen and de Medeiros' (2017) is grounded in the understanding that unscripted, imaginative play can serve as a vehicle for maintaining an authentic self and fostering connection. As these researchers noted, to reclaim play is to let go of what is "real" so as to cultivate feelings of being comfortable in being one's self, becoming fully absorbed in an activity, "standing quite consciously outside 'ordinary' life" (p. 2). Creative play, they pointed out, has the potential to open a safe space for longing and grief as well as silliness and fun, the wide range of emotions that are a part of life. The exaggerated sometimes humorous and

outrageous, other times deeply sad—arresting language and gestures of play offer imaginative possibilities that enable those struggling with a range of limitations to assume creative roles other than patient.

Moreover, play can foster connection. Play allows for interpersonal exchange, a kind of magic that arises in intimacy and can foster respect, trust, mutual acknowledgement, and risk taking (Graham-Pole & Lander, 2008). This idea of play is in keeping with the tradition of the personhood movement in working with dementia patients. It moves away from models focused on losses through dementia to recognition of the person behind the illness instead (Barnes, 2019).

Expressive Arts on Behalf

Another important inspiration for the development of my method came from Ganzon, et al. (2020). These researchers pioneered an approach to using art therapy with dementia patients on hospice they called “art on behalf”. It is an alternative to the traditional art therapy practices most often used where an individual actively participates by physically creating their own artwork with the support of a therapist. Due to the effects of illness, age and/or fatigue, hospice patients with dementia are often not likely to be physically capable of using their hands, and many are also very limited in their ability to verbally communicate. At a time when conserving their resources is a priority, hospice patients are reluctant to engage in art making and do not recognize how helpful creative activities may be (Nainis, 2008). In the palliative care field, staying active as one can without doing too much is a leading recommendation to address fatigue that has both emotional and physical aspects. Art therapists using the method of Ganzon et al. (2020) invite patients to physically make art and/or write poems or stories, but the sense of obligation to do so is completely withdrawn; the traditional terms of engagement dropped. The

therapist prompts each participant to express their own ideas, with the therapist doing the creative execution. In this sense, art is co-created on the patient's behalf instead of for them. (Ganzon et al., 2020).

Ganzon et al. grounded their method on the research findings of Korner et al. (2010) who investigated a method of producing co-created artwork that was viewed as an expression of the intersubjective understanding of the therapist and the patient. Intersubjectivity, in turn, was conceived of as a shared unconscious emotional field created out of what is in-between the client and the therapist. By making sense of personal experience through interaction with others, meanings emerged in conversation (or in between) rather than within the individual (Korner, et al., 2010). Even as the main focus was always on the patient's experience, the art therapist's attunement and reflexive awareness was key to the process. The goal was for a shared understanding that enables the therapist to create something personal and meaningful to the patient. As in a conversation between people, what is made has come from the between, rather than just from the inside of the artist. Through such interventions, improved quality of life was marked, they concluded, regardless of whether there were measurable changes in the physiological conditions that are often targeted in quantitative research. In this way, Korner, et al. (2010) affirmed what Ricoeur observed, the preparation for death is an affirmation of life (De Lange, 2014).

Method

The literature reviewed above points to ways a range of arts modalities can help hospice patients with dementia live well in the face of death. Clearly, crossing of barriers presented by cognitive limitations and finding avenues for rich nonverbal communication, intersubjectivity, and embodied expression are all key to the success of these arts interventions with dementia

patients. To build on this, I developed an integrated or intermodal EAT method for hospice companionship visits with dementia patients. Poetry and storytelling as well as non-verbal expressions such as music, movement, drama, drawing, painting and/or coloring, images, and gentle touch were all incorporated with a multifold purpose: providing emotional and spiritual comfort; fostering engagement and social connection; and helping patients reminisce and decenter into the imagination to express emotions with authenticity, fullness, specificity, structure, beauty, meaning, and, above all, playfulness.

Participants

The method was implemented with five hospice patients with dementia ($N= 5$) in Boston-area long-term care facilities. Spanning in age from 68 to 99 years old, they experienced symptoms of mild cognitive decline to advanced-stage dementia. One lived in a memory care unit, one in an assisted living residence apartment, one in public housing and two others lived in skilled nursing facilities (SNF). All were English-speaking. Four were female and one was male. Three used walkers for assistance in ambulating and two were confined to their beds. The two in bed required special staff assistance to be moved to a wheelchair, which rarely happened, due largely to COVID restrictions and schedules; only once in the six months I visited did I see one person out of bed in a chair, and the other I never saw out of bed. Although patients' daily lives were upended by the pandemic with many losses, including total suspension or tight restrictions of family visitation, for the most part, hospice services continued without alteration. The major exception being the requirement of use of personal protection equipment (PPE) and weekly COVID testing.

Each individual was made aware that participation in the activities of the intervention was voluntary and that they could end an activity or the session at any point for whatever reason.

I made a point to frequently ask if they wanted to continue, recognizing that fatigue is a significant issue. Also, I paid attention to nonverbal cues, as I recognize that for any number of reasons, including politeness, some may not say anything when they were ready to end/or and for me to leave.

Structure

Each person participated in three 50- minute-long, one-on-one sessions. Even as I always kept to a basic pattern (described below), the duration of each part of sessions varied. Similarly, the flow and sequence in between the set beginning and ending also varied. This flexibility allowed for spontaneity on my part and on that of the patients, thus reducing anxiety.

Every session began with a simple verbal greeting (“Hello. It’s Jeanie from Hospice. How are you today?”) along with a gesture of caring touch. Most often this meant my dropping down to the level of the patient, resting my hand over the patient’s hand for a few minutes, smiling with my eyes above my mask, giving my best “smize” (assuming a playful or alluring expression of the eyes) , and making eye contact, if the individual was open to this. For two of the patients with whom I had developed a close relationship over a span of six months, caring touch sometimes also took the form of coming in close and stroking their foreheads and or faces. Each and every time before touching, I first asked permission. All the sessions ended with a song, poem, prayer, or short reading, patient’s choice. And then, me drawing close, putting my hand on theirs, making eye contact, offering a smile and a verbalization; thank you so much for your hospitality. Then, just before walking out, always adding a simple, “I will be back next week”, even when I could not be entirely sure the person would be alive in a week.

The bulk of the session, the middle portion, always covered, in the language of Graham-Pole and Lander (2008), a continuum of expressive art making or play ranging from

“evanescent” to “preservable” forms (p. 84). Evanescent expressions included massage (foot and/or hand), caring touch with a plush stuffed animal, using a stuffed animal or a doll to give voice to a feeling or other role play, reminiscences (sometimes prompted by Beautiful Questions from TimeSlips^[1]), singing familiar songs most often a capella but sometimes accompanied by a recording (the patient singing along and/or being sung to), and sometimes holding hands and swaying in rhythm with music while singing. Preservable expressions included co-creating a painting and/or a poem in response to a reminiscence or story, perhaps picking up on lyrics to a song sung or played that seemed to resonate, or a short narrative from the role play (voiced by stuffed animal or doll). Sometimes a painting or wacky themed photo prompt led to a co-created narrative or poem.

The intermodal sequence and duration of each form of expressive play varied according to mood, how each patient was feeling on a given day, and on whatever constraints came from nurses or other visitors, etc. and other factors impacting me, the therapist. However, each session always covered the evanescent-preservable continuum, with different forms of expressions as responses to others. And sessions always opened and closed in the same way, with a song, poem, prayer, or short reading, patient’s choice.

Ethics of Caring Touch

Prior professional training taken by this writer on appropriate care for persons on hospice and with dementia in particular was followed. The kind of intimate caring touch used in this method is uniquely therapeutic, and highly recommended for dementia patients (Barnes, A., 2020). All the same, this investigation approached caring touch with great sensitivity and mindfully adhered to the guidelines for nonsexual touch laid out in the code of ethics for registered expressive arts therapists (REAT). I was careful to make sure the client agreed to the

touch in the context of our work together, and given the issue of memory, this meant asking for consent multiple times in a session. My focus was on promoting the therapeutic aspects of use of touch, and I was mindful not to cross a boundary into another type of relationship. Before, during, and after every session, I reflected on the question, will this be in the patient's best interest?

Results

This section provides details about implementation of the integrated EAT method described above with two of the five patients who participated. These details are presented in the form of notes, narratives that give a sense of the method's full arc and the nature of intersubjective experiences in employing it; my observations in tracking involvement in activities, emotional states or mood, verbal expressions, facial expressions, eye contact, and breathing are provided along with some of my visceral and emotional responses and thought processes. While reading notes on other sessions would give the reader more content, they are beyond the scope of this thesis; they are not essential to answer the question being explored, whether or not the method has the potential to enhance quality of life for dementia patients facing death.

Patient One (X) Session 2

Opening

Upon arriving at the memory care unit, I found X seated in the corner of the large hallway of the unit outside her room. She was dozing, slumped in her chair embracing her baby doll. The TV was blaring in her room. I squatted down at her eye level, came in close, smiled, and said, "Hello and, how are you? May I put my hand on yours?" She looked me in the eyes and said, "That's fine." I gently squeezed her hand. "Mind if I sit and visit for a while?" X looked up,

met my eyes, and with a smile said quietly, “Go ahead. Sure.” I felt my whole body relax and my spirits lifted in hopeful anticipation of the benefits for X in the play to follow.

Middle: Evanescent-Preservable Continuum

I sat down, leaned in close again, and continued looking into X’s eyes with my best smile over my mask. X responded with an even wider smile than she first gave, albeit a shy one. I leaned even closer and stroked her hair. “How shiny and beautiful your hair looks today,” I told her. I also caressed her forehead and cheek and then put my hand in my lap. While touching X, her smile grew even wider. She seemed to blossom under the touch; I could sense that her whole body was relaxing. Soon, her gaze returned to her doll baby. I sat back on her rolling chair, still quite close. Then, she took the lead in initiating play. She spoke to her doll, in a silly voice: “Suzie, don’t you bite me.” She chuckled as if this was the funniest thing in the world. And I laughed, too. And I repeated back what she said in the form of a question, aiming to match her tone and dynamics but with slightly greater playful intensity: “Is Susie trying to bite you? Oh my. How does that make you feel?” I wondered to myself if this was X’s anxiety speaking. Pause. Then, X said, looking at her doll, “Irene, don’t you bite mommy. Be a nice girl.” I held the space quietly. After a little while, X called my attention to the basket under her chair. I lifted the lid and there I found a stuffed animal. I pulled the little stuffed rabbit out and had him bounce up and down on the table, and gave him a voice, “Look at me! Look at me!” X chuckled loudly. Then X said to the bunny, “Don’t hit me!” as the bouncing rabbit came close to her arm. She pulled back a little. To her I said, “Don’t worry, X. You’re safe.” And then to the bouncing rabbit, “Mr. Bunny, be careful now. Be nice. Don’t you even think of bumping X!” X laughed. My sense was this whole first part of our play was about her feeling out her sense of emotional safety. I let bunny rest on the table for a minute. Then I brought him up to X’s neck and rubbed

him gently against her neck and cheek. “That tickles,” she said, giggling. Then I said to the stuffed animal, “Mr. Bunny, are you tickling X?” And to X: “Does his soft fur feel good?” I got no answer but a big smile. I left bunny on X's shoulder and held the space for a few moments. She stroked his fur. Then, after a few minutes, the stuffed animal fell into her lap with her doll, and she left it there.

Seeing this as a good transition time, I pulled out my large sketch pad and sharpie and box of watercolor crayons, laid them on the table and asked, “Shall we make some art together?” X. nodded. She watched my every move with striking interest. In past visits she had shown interest in this “art on behalf” time. Then, I asked her a Beautiful Question: “What is a special gift you’ve received? It can be from any time in your life.” Asking Beautiful Questions, an idea borrowed from TimeSlips (Bastings 2006), generates a sense of fun and gets people to think a little differently. Whatever a person says in response gets echoed back and written down with enthusiasm, no matter how nonsensical. For patients like X with significant cognitive decline, this has worked well to free up the flow of imaginative play and make creative connections. It has the spirit of a game and takes away any felt pressure to have a full conversation, something X cannot do.

I got my sharpie, ready to write. “Monkey was a special gift,” X explained. Monkey was a stuffed animal we had used in role play during the previous session, and in other sessions before that as well “Someone had brought it to me and left it on my table.” I learned later that that someone was X’s daughter; this connection shaped my arts-based response, as I shall discuss later on. After reflecting this back, I held the space in silence. X. then shifted to making sounds. “Oink, oink. Quack, quack. I don’t have any animals.” Again, I echoed back what she said and jotted it down. X laughed, and then spoke in the voice of her doll: “Mommy, mommy.” X.

looked at her baby doll and said, “What do you want?” And then X had the doll say, “She’s sitting on the chair I used to sit on.” By “she,” I presumed she meant me. X continued, and I continued writing her stream of consciousness. “And Monkey was looking out the window the other day,” she mused. “And Irene was saying, I don’t like it here.” The layering of meanings and feelings seemed thick to me. I just kept up my reflective listening and scribing her words. “I want to go back to Lincoln with brother Carl the cow.” Then, I looked up and reached over and put my hand on hers. I repeated again, “you want to go and be with your brother, Carl.” We made eye contact, but then she looked down at her doll. Irene was wearing an outfit with Minnie Mouse. “And I call Monkey Minnie Mouse. And he calls me to listen to the chirping birds,” she rambled. Pause. “And I think of Mother who left me a long time ago. She gave me beautiful shoes.”

Then after an even longer pause, seemingly from out of nowhere, X said, “I would like to be out in the flower garden. I love flowers.” Long pause. And then, “Mommy, please don’t go away, I’ll be lost without you.” Pause. And then. “Soon it will be spring, Soon.” Ah, I said. “Is that a good place to stop?” X nodded. The idea of TimeSlips is that at the end, you read back whatever came out in response to the prompt without any editing. And so, I did. I couldn’t tell from reading X’s body language or facial expression much about what she may be thinking or feeling. I could tell, though, she seemed engaged and relaxed.

I asked her, “Do you want to co-create a painting of those spring flowers with me?” She gave a big smile and said, “Yes.” “Shall we listen to some music while we make a painting?” Again, a nod. X told me in an early visit that she used to sing at a church choir. I also took a mental inventory of what she had for CDs on an earlier visit. Based on this, I chose a soothing classic hymn, “Come Thou of Every Blessing.” It has a simple, lilting Celtic melody. We had

sung it together during another visit and she seemed to enjoy it. In this moment, I hummed along. Then I opened the metal lid of the long box of watercolor crayons: “What colors shall we make the flowers?” I asked. She pointed to pink and purple. And green for the leaves, I asked? Which greens? She selected three crayons. Then she watched me with interest as I made shapes with my sharpie and filled them in, blending the colors she’d picked. “Did I get it right?” I asked. “Does this look good?” She gave me a smile and nodded.

Closing

With four minutes remaining, I asked if she wanted me to read a poem before I left or play another song. She shrugged. X has not shown difficulty with endings. Then I picked another song from those linked to the one I had been playing, “It Is Well with My Soul.” I packed up the pad and the art supplies and sang along. We made eye contact. X didn’t sing this time. After a few verses. I leaned in close, clasped her hands and swung them back and forth to the slow rhythm. Her arms were a little stiff when we started swinging, but she visibly relaxed as we went along. She gave me a big smile, and my sense was she enjoyed it. When the music ended, I said my usual, “Thank you so much for your hospitality, X. I really enjoyed our visit.” And I leaned in to squeeze her hand. X replied, as usual, “Thank *you*.” “I’ll be back again next week,” I said, and turned and walked over to the elevator. Standing there I smiled at her from across the hallway while I waited. As I left, I gave her a wave. I felt a tug in my stomach. She seemed so sad. I thought of her words for Irene the doll, “I don’t like it here.” Before the elevator arrived, X had slouched back into the position she was in when I left her. No more eye contact. And I felt sad to leave her. I breathed deeply and silently repeated the mantra I repeatedly used during sessions to help me: “I can’t fix this. I am doing the best I can with what I have.”

Patient One (Z), Session 3

Opening

Upon arriving at his room in the skilled nursing facility (SNF), I found Z lying diagonally on his bed, legs hanging off, bent at the knee, feet bare. He is too large for his bed and likes to lie this way I have been told by staff. I greeted him with the usual, hello, how are you? and looked into his eyes, smiling wide with my eyes (smize) over my mask. He growled, TERRIBLE! I echoed back, attempting to register the intensity and volume of his growl and take it up a notch. “You feel TERRIBLE. Do you have pain?” “Yes,” he explained. “Where?” He told me his stomach hurt. I put my hand to my stomach, mirroring his gesture. “I am sorry you don’t feel well,” I replied aiming to express empathy with tone of voice. And silently I spoke to myself what had become my mantra, “I can’t fix this, I wish I could take this away and I know I can’t.” Again, I spoke, “I am sorry your stomach is hurting, Z.” Then I spoke aloud idea that had come to me in the silence. “I can offer you a hand or foot massage? Would you like that?” He said, “Yes.” right away. “How about foot massage?” I asked, seeing the setup of his room, and his body position, feet dangling over the edge, would make this easiest and perhaps most soothing. He nodded, and I began.

Middle: Evanescent Preservable Continuum

Using my almond oil, I gently and slowly started rubbing the soles of Z’s feet, and then moving to massage each of his toes, one after another. While I gently massaged, I hummed part of a song he had asked for during a previous session, “Teach Your Children Well” by Crosby, Stills, Nash, and Young. His facial expression soon shifted from a tight grimace to a relaxed wide grin, eyes closed. He was clearly enjoying the touch. “Does that feel good?” I asked. “Oh yes,” he replied. I asked him to let me know if at any time he wanted me to stop. His feet were very tight and cramped when I began, but after a short time I could feel the knotted muscles

release, soften and relax with the gentle massaging. And I could see the tension he had been holding in his shoulders releasing some. I kept rubbing his feet and humming. And after a while, Z.'s breath seemed to become slower, his stomach and chest now gently rising and falling; his torso had seemed tight when we started. His breath was initially shallow, and now was much deeper. The expression on his face seemed to say peace. Then, after some time of quiet, I asked him if he wanted to play the game of answering a Beautiful Question or two. He replied, "Sure." (I have used such prompts before). My first question was: What is a sound you find beautiful? He didn't miss a beat. "A KANGA DRUM!" "Ah," I said, with enthusiasm. "Tell me more about that!" I added, trying to match the same energetic inflection with which he spoke his answer, or even slightly heightened. Z went on to say that he and his brother used to play drums together. Big wide smile. And then a cloud passed over and he added, "I miss my brother." I echoed back what he said, matching his tone and dynamics, and held the space. After a long pause I then asked, "Is there anything else you want to tell me about drumming or times with your brother?" I knew they had played in a band together and had heard stories about this during earlier visits. He shook his head and was silent. Pensive. I kept rubbing his feet in silence.

Then, after a while, I asked, "Do you want another Beautiful Question?" "Sure," he replied. "What is a special gift you've received that stands out for any reason?" I asked. Again, Z answered right away: "My teddy bear. The teddy bear my daddy gave me when I was six or seven." And I echoed this back, aiming for the same tone, dynamics, and tempo. And added, "Tell me more about your bear. What did he feel like? Color fur? How big was he?" These prompts led to him describing the bear, Teddy, with glee, how very soft his fur was and how he loved to hug him and snuggle him close in his arms. Other times I have brought a plush stuffed

animal and used this and a stuffed bear he had in his room for comfort touch and role play with Z.

Each visit these plush stuffed animals served as a strong, multi-layered sensory connection for awakening his imagination, I had noted. In this moment, Z. then offered a poignant narrative, Teddy told me where to go to be safe when the house my father built burned down. I let out an, “Oh.” And then I echoed what Z. had said back to him, again aiming to match and slightly amplify his tone and dynamics. And I added, how did you feel? He responded with, “Scared. Very scared.” Then he was silent. I held the space. Waited and then he added in a wistful frail voice, “Is there a safe place?” I echoed this back and then added, “That is a hard question. I wonder.” And held the space. I made a mental note that it may be helpful to come back to this. Then I asked, “Did you have to move after the house your dad built burned down?” “Oh yes,” he replied. “Did you move nearby?” I asked. “We moved closer to the teddy bear factory,” he offered. “And then I got to get lots and lots of teddy bears. They covered my bed and were all over the house,” he said gleefully. Again, I echoed back his words and asked, how did that make you feel? “Oh, very good. Yes, very good.” I noticed much color had come into his face and he bore a big smile. His body was relaxed and breathing seemed deep and even.

Next, I stopped massaging his feet, and said, “Shall we make a poem from your memories?” We had done this before, and Z. nodded and gave a clear yes. I jotted his words down in my big sketch pad, and then read them back. “Is there something else we should add?” He shook his head. “No. You’ve got it.” Then I asked another Beautiful Question. “Is there a special gift you gave someone else that stands out for any reason?” He started to tear up. His face became red. His body tensed up again, as he held back sobs. “Yes. I gave my best friend, Jimmy, a teddy bear because he had lost his.” His grief felt enormous to me. And I knew this wasn’t just

about the loss of a stuffed bear his or a friend's in childhood. "Oh, Z," I said, and again echoed his words and tried to match his tone and dynamics. "I can see that you have a lot of big feelings." As I said this, he let out some more tears. I kept massaging his feet, holding the silence. Then, after a while, I spoke. "Is there anything more you want to say about this?" Z replied, "I felt so bad for Jimmy and what he went through." I can see that. And what stands out to me, is what a kind thing it was for you to give him the gift of your teddy bear. You have a beautiful, big heart, Z." I then held the space, gently rubbing the instep of one of his feet which I noticed had cramped up a little.

Then after a long moment, I set down his foot, and started writing what I remembered of what he had spoken. When I finished, I asked, "Do you want to hear what I've written down from your memories? A kind of poem we've co-created?" He nodded. A big wide smile spread across his flushed face, while he listened, eyes closed. Then I asked, "Did I get it right?" "Oh yes, he said approvingly. "That is wonderful." At this point, I knew I needed to pull the session to a close, so I asked him if there was anything he wanted to add. He shook his head no. You've got it. I then said, "What if we make a picture to go with this? What would you want to see?" He answered. "Me hugging teddy." And so, I quickly sketched a big image for him of a bear being hugged. "What colors shall we make this?" I opened my big box of watercolor crayons. He studied the wide range of beautiful colors. Then, slowly, one at a time, he pointed to four different shades of blue. As I then began to make the picture on his behalf, Z. shifted his body up so he could watch.

I vigorously rubbed and blended the different blues, and then took out the brush, dipped it into my water bottle, and spread the colors in a luminous watery wash. His smile gave away how much he was enjoying the process. Then I asked, "Is this a fit?" I asked him. He smiled. "Yes.

But teddy needs to be dark, dark brown,” he said. “Ah,” I said. And then I followed his lead. Choose some browns for us, I asked. He pointed, and I took out the watercolor sticks. I grabbed my Sharpie and made a new shape, a very large bear. I then colored and painted with a thick wash of burnt umber. Before I went too far, I asked, “How is this? Do you like it?” “Yes!” he replied enthusiastically. I echoed back the “Yes,” with the slightly greater intensity and volume, and flashed a big smile over my mask. While still painting, with four minutes to go, I let Z know I would need to be leaving soon. I asked him to think about whether he would like to end with me singing a song or reading a poem. “You don’t need to answer right away,” I said. “Just think.” Then I added, “And what do you think of the idea that, next time I come, we make a big picture of your house, and you can show me where all the teddy bears would live? He seemed delighted by the idea: You are a teddy bear angel!” he said smiling.

Closing

I smiled, and asked: “Poem or song?” Poem, he answered. I then read him a short one, “Fog” by Carl Sandburg. Z. closed his eyes while listening and smiled. When I finished reading, I reached over, put my hand in his hand and squeezed gently. He opened his eyes and made eye contact with me, his eyes sparkling. I took it as clear sign of pleasure and connection. I then thanked him for his hospitality and told him I would look forward to seeing him next week. He replied with a hearty, “Thank YOU.” I turned and walked out of his room, feeling very moved by the power of emotional connection, the enhanced quality of life for both of us.

Discussion

The question — How can the use of expressive arts therapies on behalf of individuals with dementia promote aspects of living well in the face of dying? — was explored throughout this capstone. The development and implementation of an integrated EAT method aimed to serve

the multifold purpose of providing emotional and spiritual comfort; fostering engagement and social connection; and helping patients reminisce and de-center into the imagination to express emotions, above all, with a sense of playfulness. The results showed these aims were met and supported findings in the literature review. Patients' verbal and especially nonverbal expressions indicated that engaging in EAT improved their quality of life, for the duration of the sessions. Some of the notable findings include the effectiveness of caring touch; given high levels of sensory deprivation for these patients, particularly since the level of their isolation during the pandemic was extremely high, gentle massage and all forms of touch clearly helped individuals relax. It laid the ground for taking risks in play, making social connections and exploring a range of verbal and nonverbal expressions. Allowing for flexibility, improvisation, and following intuition all reduced stress and opened the way for greater spontaneity. The point was not to try to analyze the meanings of patients' expressions, but to bear witness and create space for an individual's own connections and possible meaning making, whether conscious or unconscious. I felt this goal was met. The intersubjective experience of implementing the method was a most powerful one. In potent ways the experiences facilitating sessions, co-creating and/or making art of behalf of these individuals with dementia facing death profoundly enhanced my quality of life, and gave me much to ponder.

However, a more ambitious goal of sustained, marked improvement in the quality of life between and beyond these sessions was not attained. Both X and Z declined in the week following the end of sessions implementing and tracking the method (not the end of my visits, however). X got a sepsis infection and had to be hospitalized. He survived this but returned to the SNF weakened and with reduced verbal and physical acuity. X stopped eating and refused to get out of bed as of this writing.

Examining the context of life in long-term care facilities in the context of the pandemic is important to understanding the significant limits in sustained effectiveness of any method employed by a weekly hospice professional. Due to COVID-19, for the full year preceding the month of implementation of the method and during it (February 2020 to March 2021), profound loss was the salient reality for all living in long-term care facilities and not just those with terminal illnesses. Loss took many forms: complete suspension of family visitation and then strict, limited allowances for visits; suspension of day-to-day programming—only resumed minimally just before February when I implemented the method. Two participants were confined to their beds. In the memory care facility where X lived, some restrictions had been eased but not the suspension of family visitation. In the SNF where Z lived, all restrictions stayed in place for him. And, of course, loss during the pandemic took the form of widespread death of members of their community. Nationwide this was the case. Although less than 1% of the US population lives in long-term-care facilities, this tiny fraction of the country accounted for 34% of US COVID-19 deaths as of March 4, 2021, the end point of the implementation of my method. (The COVID Tracking Project, 2021). Z's spouse lived in the same SNF and died during the Spring of 2020. Another individual on my caseload experienced the same wrenching loss of a spouse due to COVID. One patient who participated had had the virus, was hospitalized during the spring of 2020 and survived.

The world, the US included, is only just starting to come to terms with the devastating impacts of the ongoing pandemic, factors that weekly visits by hospice professionals cannot make up for. A 75-year old woman profiled in the *Washington Post* put vivid words to experiences not unlike what I have witnessed in my patients with less verbal acuity:

A day can drag on forever when you're isolated all by yourself. I sleep as late as I can. I

try not to look at the clock. I go on Facebook and read about all the ways this country is going to hell in a handbasket. I turn on the TV to hear a bit of talking. It's been almost seven weeks since I've spent time with a real, live person. I haven't touched or really even looked at anyone, and it's making me start to think recklessly. (Saslow, 2020)

That description was written after two months of lockdown. A year into the pandemic, it has become clear that its impact of is greater than just intolerable loneliness or boredom and has direct bearing on hospice work. Columnist William Wan explains, individuals with dementia are dying at unprecedented rates. They are dying “not just from the virus but from the very strategy of isolation that's supposed to protect them. In recent months, doctors have reported increased falls, pulmonary infections, depression and sudden frailty in patients who had been stable for years” (September 2020). Isolation is a killer for dementia patients, one that playful caring relationships with expressive arts therapists cannot protect them against. While my visits providing a carefully choreographed method clearly engaged, offered comfort, and enhanced quality of life for to these hospice patients with dementia and for an hour a week, they did not and could not do enough to offset the overwhelming losses brought by the pandemic.

Consequently, it is very difficult to draw conclusions about the efficacy of the method outlined in this capstone to enhance quality of life in the face of dying in any sustained way. To make a start toward this, it would be most helpful to repeat it after the pandemic with hospice patients with dementia and significantly increase the number of participants and number of sessions. Beyond this, once family visitation restrictions are eliminated, a helpful modification of the method would be including caregivers in sessions so as to support patients in carrying over particularly resonant parts of the method into everyday life between sessions and after they end. For example, caregivers might offer gentle hand, foot, and/or shoulder massages with aromatic

oils. They might play music while feeding patients and when finished, hold their hands and sway in time with the rhythms and sing along. Creating playlists for patients that they can easily access on their own devices available to them could be another daily extension to raise quality of life. Activities directors could try implementing the method with groups, and in this way help individuals make social connections with members of the community they are spending their days with.

Conclusion

Clearly, integrated EAT may offer a framework for people with dementia on hospice to develop greater sense of social connection in the here and now and express complex emotions and thoughts in powerful wordless ways. Although sustained benefits would be amplified in non-Pandemic context, some benefits are evident even within the context of COVID conditions. I witnessed how a method employing integrated EAT helped bring out individuals' sense of self, their unique personhood. I witnessed resilience and sense of spiritual strength and well-being emerge.

Moreover, from my experiences in this investigation, journeying with individuals with dementia facing the end of life, I have learned volumes – perspectives and approaches and skills transferrable to any population. Perhaps the most salient gift of learning and growth as a clinician was my cultivating greater patience and the inner peace needed to slow down and let the patient (or client) take the lead in play. In the last analysis, I have discovered that when I breathe, relax, and allow my own quality of life to be enhanced — when I drop any urgently felt impossible need to fix, make all better, and instead simply journey alongside another human being in all their mystery with empathy and compassion — I am much better able to serve and guide. This surrender of head to heart is the essential element of the method.

[1] A “Beautiful Question” is an open-ended question with no right or wrong answer, designed to open a shared path of discovery. For example, what is a sound you find beautiful? A special gift you have received? A gift you gave to someone? How might you make a new person feel welcome? These questions were only used with those in early stages of dementia.

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**THESIS APPROVAL
FORM**

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Division
Master of Arts in Clinical Mental Health Counseling: Expressive Arts Therapy, MA**

Student's Name: _____ Jeanie Cooper Carson _____

Type of Project: Thesis

Title: _____ Beyond Bingo: Enhancing Quality of Life in the Face of Death for Hospice
Patients with Dementia Through Integrated Expressive Arts Therapies,
Development of a Method

Date of Graduation: _____ May 22, 2021 _____

In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: _____ Denise Malis _____